

# Epilepsy emergency rescue training

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## Abstract

The NICE audit of epilepsy related deaths revealed that 1200 epilepsy deaths occur every year in the UK, with 42% potentially avoidable.[1] Convulsive status epilepticus (SE) is a life-threatening condition with over 20% mortality rate, especially if early treatment is not initiated .[2] Ten percent of all UK emergency department (ED) admissions are due to epilepsy, usually over represented by cases of SE.[3] Six out of seven epilepsy cases seen in the ED are admitted into medical care.[4]

Patients with chronic and/or treatment resistant epilepsy carry a higher risk of premature death. When a seizure lasts for five minutes or more then the patient is at high risk of continuing to SE and this may result in causing brain damage or death.[2]

Buccal midazolam is an emergency rescue medication prescribed on a special named patient license to reduce the duration of an epileptic seizure and prevent SE.[2,5] It should be administered by a trained person and is widely used due to its effectiveness and social acceptability. In the UK, epilepsy education and training courses are expected to be conducted by epilepsy professionals in line with the agreed training guidelines of Joint Epilepsy Council (JEC) backed up by evidence from NICE.[6,7] Training should provide an overview of epilepsy to facilitate safe care and appropriate administration of rescue medication for people with epilepsy (PWE) when experiencing a prolonged seizure. The medication is prescribed on specialist advice by the GP or specialists directly.

Unfortunately the JEC guidelines are not robust enough to provide assurances of safe care. This problem had a myriad of complexities and an appropriate solution using web based resource was piloted, tested, and applied successfully using quality improvement methodology.

## Problem

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There are significant associated cost implications in paramedics attendances and emergency hospital admissions if risk assessments and emergency care plans are not understood or in place for the individuals affected.[8] The effectiveness of BM for individual patients could be wrongly called into question by prescribing authorities if a serious incident happens.

The main identified gaps/concerns leading to the problem are:

1. The loose structure of the JEC guidelines allows people connected to epilepsy (but lacking relevant skills and competencies) to set themselves up as trainers as there is a lucrative financial market in delivering such training. This in turn could lead to improper education of carers
2. The prescribing of the medication is done on recommendation of epilepsy specialist doctors either directly or via the GP. In such situations, the prescriber has no direct mechanism of assuring themselves of the safe use of the medication at relevant times, particularly if the trainer is working independently of the prescriber and the prescriber has no feedback system to enable confidence in the trainer to support their prescribing
3. Even among qualified trainers (such as specialist epilepsy nurses) the practice of training, duration, recommendations, individual guidelines, and focus varies significantly based on UK regions, and there is no systemic mechanism to assure consistency of practice[9]
4. The trainees come from diverse backgrounds including families, organizations, ethnic, and social cultures. There is

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no consistent mechanism to give assurance of how much of any training has been understood and thus likely to be applied

5. There is more than one BM preparation available with different administration advice, which may confuse carers particularly when generic substitution with anti-epileptic drugs is common.

### Background

Current guidelines recommend immediate treatment of a people with epilepsy (PWE) where there is proven risk of seizures becoming life threatening, for example seizures lasting more than five minutes that may progress to SE and/or neurological morbidity. Seizures that last more than five minutes are less likely to terminate spontaneously. For obvious reasons, whether or not they receive their treatment in time depends on the presence of another person (such as a family member or paid carer) trained in recognizing the situation, being able to analyse it as trained, and then administer rescue medication. The Joint Epilepsy Council guidelines on epilepsy training tries to deliver this.

However, it is recognized that the situation varies dependent on:

1. Regional variation in service provision in the UK
2. The diverse range of specialties of trainers which may influence their depth of knowledge about epilepsy
3. Lack of a clear structure for training including length of training, topics to be covered, feedback systems on both the training and the trainer, etc
4. Lack of a clear structure to check and support the competencies of trainers such as peer groups, good practice portfolio etc
5. Diverse range and background of trainee groups including paramedics, family member, and paid carers
6. Duty of care responsibilities are unclear, especially given the poor understanding of outcomes such as high risk of death when things are not done properly
7. A complex pathway which includes different groups/agencies such as specialist, GP, family, and paid carers needing to react in a structured and systemic manner to ensure safety of an individual who is unconscious
8. Dependent on resources available locally.

### Baseline measurement

In a local clinic commissioned for patients with intellectual disability (ID) and epilepsy over two years it was consistently noticed that 20 to 30% of carers of people with epilepsy (PWE) on rescue preparation of midazolam were not able to give satisfactory confidence to the prescriber of their abilities to manage an emergency involving rescue preparation in spite of rescue medication training in the previous year.

Around 25% of PWE are considered to have ID. Fifty percent of those with severe to profound ID have seizures of which 50% are treatment resistant. Given the over representation of health

problems, treatment resistant epilepsy, complexity of treatment, problems in communication, and informed decision-making, the group with ID is significantly over represented in the population on midazolam.

There were two main areas of concern:

1. Despite "training" carer and professional understanding remained poor
2. There were a wide variety of trainers with different backgrounds some with teaching that was inconsistent with current good practice.

### Design

A good training package should include standardised assessments developed by peer group and relevant stakeholder consensus to demonstrate evidence that competencies had been acquired. We used quality improvement methodology to develop a standardised peer reviewed 30 minute video-based e-test to enable epilepsy trainers across the South West of the UK to assess their course attendees' understanding of delivering good care and rescue buccal midazolam (BM) medication.

The e-test includes random videos to examine a candidate's ability to identify practical procedures required in keeping people with epilepsy safe, including BM administration. The aim was to ensure the trainee had gained the necessary knowledge during training. There are "essential" and "desirable" sections. A candidate must achieve a 100% correct response rate in the "essential" section in order to pass, and get at least 50% in the "desirable" section. The e-test had a robust audit process built in for quality assurance.

### Strategy

PDSA cycle 1: The test was piloted among the South West epilepsy nurses group and the local neurologists, neuropsychiatrists, and other clinicians (including GPs), learning disability consultants, and nurses. Service user opinion was sought from a diverse set of the population, including individual service users, carers, and residential homes and private organizations which avail the training for their employees. There were a total of 25 participants. Based on feedback, changes were made to the style of questioning, the robustness of questions, and the structure of presentation. A temporary website portal for further piloting and to gain anonymous feedback was created.[10]

PDSA cycle 2: The e-test was first piloted with 100 carers attending local epilepsy training courses chosen randomly. A 20% failure rate showed a potential risk of bad practice, despite having been "trained". Feedback by the candidates resulted in changes to the programme. The e-test was then put to consultation with national epilepsy experts and national epilepsy charities. The e-test was tested for quality standards and received support as a source to improve patient safety by the Joint Epilepsy Council and other national and regional organizations. It was launched on the 17/09/2013 at the South West epilepsy conference.

## BMJ Quality Improvement Reports

PDSA cycle 3: In the year post-launch a further 723 carers of people with epilepsy (separate to the first 100 carers) took the test on the temporary created website. The analysis of results and the feedback confirmed the robustness of the package. The package was then adopted by Cornwall Council who now recommend that all organizations and carers who are involved with PWE on rescue preparation take the test. The resulting audit trail for organization managers allowed them to request sight of the candidate's certificates (which the Cornwall Council website awards) strengthening the governance process. The comparative results of the three PDSA cycles are shown in graph 1.

### Results

Between 17/09/2013 to 17/09/2014, 723 carers of PWE have taken the test on the test website [www.epilepsy-education.com](http://www.epilepsy-education.com) (this has now been dismantled as it was the test site).

One hundred and fifty-two (21%) failed the e-test thus, one in five patients on buccal midazolam were at risk of inappropriate BM delivery in a condition where there is at least 20% mortality. Four hundred and twenty-seven of the 723 carers provided feedback.

Feedback questions (agree/strongly agree):

1. Is the website and quiz easy to access and use? (82%)
2. Do you feel the test makes epilepsy patients' lives safer? (94%)
3. Is the content of the correct standard to assess practice improvement? (89%)
4. If a family member or relative of yours had or develops epilepsy, would you like their carers to take this quiz? (95%)

The comparative results of the feedback questions are shown in graph 2.

No ES related deaths occurred in the local ID epilepsy Cornwall services since the enhanced training package was put in place. Better training and improved reporting/awareness has improved seizure stability supporting withdrawal of buccal midazolam in one third of patients taking it. If BM is not used as an emergency medication for at least a year, we suggest that it is a surrogate marker for significant improvement in seizure control and thought then needs to be given to its withdrawal from the patient's medication regime as the risks of administering it could outweigh the benefits. Thus withdrawal of BM signifies a significant reduction in the risk status of the person.

The intervention has a significant positive impact on patient safety, prescribing costs, and was anecdotally evidenced by reduction of paramedic call outs and ED admissions.

See supplementary file: ds5413.docx - "Graph 1 & 2"

### Lessons and limitations

On the face of it the problem seemed simple; it appeared that a

structured training programme was requisite. However, on inspection it was clear that there were diversity of needs, especially as basic epilepsy awareness depended on different patient populations and their bespoke needs. It was thus felt that a summative quiz/test using the "driving licence" model (where different trainers provide input but the final test is standardised) was the best method to harmonise this. It was also hoped that the availability of a structured assessment tool would allow the differing training sources to achieve a standard that would ensure the quality and safety of the trainees.

The designers and stakeholders of the test realize that there are significant limitations and the test is in place as a minimum standard rather than a gold standard for care delivery. It is appreciated that the tests examines the comprehension of the theory of the process in the trainees and not the actual practice at the time of need.

Feedback from trainers and trainees is allowing a stricter training curriculum to ensure patient safety.

### Conclusion

The e-test is recognized as a novel resource bench marking competency in a grey but critical area of care delivery. No SE-related deaths have occurred in the local ID epilepsy service since the enhanced training package was put in place. Better training and improved reporting and awareness has improved seizure stability supporting withdrawal of BM in one third of local patients. The intervention has had a significant positive impact on patient safety, prescribing costs evidenced by reduction of paramedic call outs and ED admissions.

The website uses innovative IT to improve patient outcomes and addresses the problem of inconsistency. The design and implementation is novel, cost effective and has a high impact. Twelve months of operating the e-test identified 21% failure rate. Re-training of these carers has ensured that people with epilepsy are safer from potential inadvertent harm. All carers of PWE prescribed BM in Cornwall are encouraged to take the test. The local NHS Trusts and Cornwall Council have adopted the e-test programme evidencing the e-test's organizational efficiency and delivering benefit to patients.

Private organizations contracted by the Cornwall council would need to provide assurances that the minimum training standards are being met by using this e-test particularly if a serious incident occurs whilst in their care. Sixteen thousand carers for PWE working in Cornwall will hopefully reach a minimum level of competency. The website was created in partnership with patients, charities, and engagement with a large range of stakeholders including JEC. A web-based delivery portal allows fast dissemination of good practice and it is convenient for learners to use in a place and at a time that suits. The test forms an important part of the feedback loop to review and continually improve the training. The South West UK epilepsy nurses group is approaching their local councils to adopt this test as pioneered in Cornwall, with plans to roll it out across the UK. It has been presented at the South West neurological commissioning group in the hope that other

professionals with involvement in the care and provision of services for PWE are aware of the potential to significantly improve patient safety at little or no cost, and with likely cost savings.

## References

1. Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy—death in the shadows. The Stationery Office
2. Betjemann JP, Lowenstein DH. Status epilepticus in adults. *Lancet Neurol* 2015 Jun;14(6):615-62.
3. The King's Fund - Emergency hospital admissions for ambulatory care-sensitive conditions: identifying the potential for reductions  
[http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/data-briefing-emergency-hospital-admissions-for-ambulatory-care-sensitive-conditions-apr-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/data-briefing-emergency-hospital-admissions-for-ambulatory-care-sensitive-conditions-apr-2012.pdf)
4. Dixon PA, Kirkham JJ, Marson AG, Pearson MG. National Audit of Seizure management in Hospitals (NASH): results of the national audit of adult epilepsy in the UK. *BMJ Open* 2015;5:e007325 doi:10.1136/bmjopen-2014-007325.
5. Brigo, Francesco et al. Nonintravenous midazolam versus intravenous or rectal diazepam for the treatment of early status epilepticus: A systematic review with meta-analysis. *Epilepsy Behavior* 2015.  
<http://dx.doi.org/10.1016/j.yebeh.2015.02.030>
6. Joint Epilepsy Council. A Guideline on Training Standards for the Administration of Buccal Midazolam. 2012.
7. National Institute for Health and Care Excellence. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE clinical guideline 137. London: National Institute for Health and Care Excellence, 2012.
8. Kortland, Lena-Marie et al. Cost of status epilepticus: A systematic review. *Seizure Eur J Epilepsy* 2014;24:17–20.
9. Epilepsy Action. A Critical Time for epilepsy in England. A study of epilepsy service provision in England by Epilepsy Action. Epilepsy Action 2013.
10. Testing Competency in Delivering Epilepsy Protocol Medication ACNR 06/2014;14(2):31.

## Declaration of interests

Nothing to declare.

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## Ethical approval

No ethical approval was needed as this was a service improvement project.